

**CT General Assembly  
Insurance & Real Estate Committee Public Hearing  
February 3, 2015**

Testimony in Support of SB 15, AAC Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

Submitted by: Katie Zigmond, 43 Wood Road, Redding, CT 06896

Senator Crisco, Representative Megna and members of the Insurance & Real Estate Committee. My name is Katie Zigmond, and I am the mother of a ten year old boy with PANDAS/PANS.

I knew that something was "off" with my son from the time he was a newborn. From infancy through childhood, his symptoms included anxiety, hypotonia, blocking/stuttering, sleep apnea, feeding issues, poor oral motor skills/strength, fatigue and lack of stamina. Over the years, I took him to many specialists, including a physical medicine doctor, a pediatric gastroenterologist, a feeding clinic, and two different neurologists. He had Speech Therapy, Occupational Therapy, and Physical Therapy. He was finally diagnosed with PANDAS by an Immunologist at age 8.

We currently have a team of doctors, including an Immunologist, an Integrative Pediatrician, a Neuropsych, a Lyme-literate Pediatrician, a Pediatric Gastroenterologist, and our regular Pediatrician. Many of these specialists are considered "Out of Network" and insurance does not cover much of the out of pocket costs. Visiting any doctor or specialist that does not understand PANDAS/PANS is a waste of time, money and energy (and is also terrifying in this climate of medical kidnappings), so we pay out of pocket. We would love to add a psychologist/therapist to our team, and try additional complementary therapies, but we just can't swing another expense at this time. Instead of hobbies, fun activities or vacations, we have doctor appointments.

Our son is currently on long-term antibiotics, and has also had IVIG (intravenous immunoglobulin) treatments, which have helped immensely. Unfortunately, such treatments are at the mercy of insurance companies. Even though our son qualifies for those treatments due to other autoimmune/immunological conditions that he has aside from PANDAS/PANS, we still worry that the expense will cause insurance to stop treatments. IVIG is currently the treatment of choice for my late mother's rare autoimmune condition, and I wonder if it is as difficult for patients with that diagnosis to get treatment. In her book, "Brain On Fire: My Month of Madness" by Susannah Cahalan, she details her recovery from Anti-NMDA-receptor Autoimmune Encephalitis through treatments of antibiotics, plasmapheresis, and IVIG. PANDAS/PANS is also a form of autoimmune encephalitis, but with different triggers. The book was a best seller, and is currently being made into a movie; obviously, the story resonated with readers. Why, then, are our children often left to suffer?

Our son has been affected academically, as well. The "waxing and waning" of his symptoms baffled his public school teachers. He has lost cognitive skills, most notably in executive functioning, writing and math. He is easily frustrated. When we first got his PANDAS/PANS diagnosis in 2012, we asked for an Individual Education Plan. The school initially refused, and spent the remainder of that school year and the 2012-2013 school year stalling. Instead of acknowledging his medical condition (we provided them with a letter from his doctor), the Special Services administration treated our son like a behavior problem and a bad kid. We had to pay for a Parent Advocate to attend multiple PPT meetings with the school. His grades suffered, as did his self-esteem. At the very end of April 2013, he was finally granted an IEP, but it was too little, too late. We enrolled him in private school the following Fall. We are not pleased that our ever-increasing taxes pay to educate other people's children, while we spend our retirement savings to send our children to private school, but we have to do what is best for them. He is doing well in a school setting that recognizes that his challenges are medical and not behavioral, and that makes appropriate accommodations for him. What happens to the kids who do not have the opportunity to escape an environment that adds to the stress they are already experiencing? Many parents opt to homeschool and report that it works well for their families. Many families do not even have that option. Those families are at the mercy of school systems that lack awareness of PANDAS/PANS or those that choose to remain ignorant.

PANDAS/PANS is not rare; it is rarely diagnosed. I know of approximately 10 other families in my small town that are affected by PANDAS/PANS, and many families in surrounding towns. Two hundred individuals attended a PANDAS conference hosted by The New England PANS/PANDAS Association in Norwalk, CT last November. In many of those families, early detection and treatment with antibiotics resolved all symptoms. If we can increase awareness of PANDAS/PANS, and get insurance coverage for treatments, more children can have the opportunity to recover more quickly and avoid the financial and emotional costs of chronic illness.

Please pass SB 15, AAC Health Insurance Coverage for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections.  
Thank you.